

SCOTTISH HOME AND HEALTH DEPARTMENT

SCOTTISH HEALTH SERVICES COUNCIL

The Young Chronic Sick

*Report of a Sub-Committee appointed
by the Council*



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The Young Chronic Sick

CHAPTER I

INTRODUCTION

1. At their meeting held on 22nd June, 1960, the Scottish Health Services Council appointed us as a Committee with the following terms of reference:

"To consider arrangements for the care and treatment of young people suffering from some form of chronic illness other than mental illness; and to make recommendations."

2. At our first meeting we agreed that, although there were continuing problems in the treatment of the chronic sick, it would be appropriate for us to confine our investigations to the age group 1 to 35 years. For the purposes of our work we defined the young chronic sick in the following terms:—

"The young chronic sick comprise those persons aged 1 to 35 years who require long periods of supervision, care, training or rehabilitation because of impairments to and deviations from normal health which are permanent or which leave residual disability."

We considered that maladjustment did not come within our terms of reference, except where it was secondary to some other condition which came within the formula set out above. Similarly, we considered that mental deficiency was outside our remit except where it was accompanied by some other condition coming within the formula.

3. We began our investigations by inviting written evidence. Those giving evidence were asked to answer the following questions:

Size of the problem

How many young chronic sick people are there?

How many need active treatment?

How many need full-time nursing care?

How many need part-time nursing care?

How many need only residential accommodation?

Nature of the problem

Are the existing services adequate?

If not, in what ways are they inadequate?

What suggestions could be made for improvement?

What are the existing arrangements for liaison between the various interested bodies?

Are these adequate?

Is there any shortage of trained personnel to care for the young chronic sick?

Are rehabilitation and training facilities adequate?

What kind of difficulties have you encountered in dealing with the young chronic sick?

4. A list of those who provided evidence is given in the Appendix to our report. We would like to take this opportunity to thank all those individuals and organisations who provided written and/or oral evidence.

5. A summary of our conclusions and recommendations is given in Chapter X.

CHAPTER II

THE NATURE AND SIZE OF THE PROBLEM

Nature of the Problem

6. The people with whose problems this report will deal form perhaps the most unfortunate group in any community. Nearly everyone experiences acute illness at one time or another, and some develop chronic disabilities after a useful and active life; but there is a unique quality of tragedy present in the lives of young people who see ahead of them years of isolation and of exclusion from the activities of their more fortunate contemporaries.

7. It seems to us a proof of the community's essential concern for such young people that for many years voluntary societies and organisations have done an immense amount of good work for particular groups of them — for example, spastics and epileptics. This work has been of the greatest value, and we hope that it will long continue. At the same time there seems to have been little attempt — at least in recent years — to study the wider problem of the young chronic sick as a whole; and this is what we are seeking to do. The nature of the problem is to identify the special needs of this particular group of people; to see how far these needs are being met at present; and to suggest methods of meeting any deficiencies.

Size of Problem

8. A fundamental difficulty which we encountered early in our work was that of forming an estimate of the total number of young chronic sick people. Certain individual organisations were able to give some indication of the numbers in the groups with which they were particularly concerned, but these estimates were frequently qualified by reservations of one kind and another; and it soon became obvious that there was at present no one source of reliable information on the total size of the problem.

9. It may nevertheless help to put the problem in perspective if we quote some of the figures which were brought to our notice. The British Paediatric Association told us that there are about 1,000 new cases of congenital heart disease per annum in Scotland. The Association also reported an incidence of cerebral palsy of 2.04 per thousand in children of school age; and figures which they and the Scottish Epilepsy Association provided on epilepsy suggested that the incidence is 4 to 5 cases per thousand in the population of Scotland as a whole. The Scottish Branch of the Haemophilia Society told

us that there are approximately 220 known sufferers in Scotland (all males): half of these are regarded as chronic sick because they suffer repetitive spontaneous bleeding throughout their lives. The Glasgow and District Branch of the Muscular Dystrophy Group estimated that about 1,000 people in Scotland, two-thirds of them children, suffer from this disease.

10. We would like to emphasise again in concluding this chapter that, while we think it essential that more comprehensive statistical information about the young chronic sick be assembled — and indeed we suggest later a method of doing this — we are concerned essentially to see the individual human problems properly tackled.

CHAPTER III

ASCERTAINMENT

11. We have spoken in the previous chapter about the lack of comprehensive information on the incidence of different kinds of chronic illness in young people. This lack of information does not necessarily mean that chronic illness is not being diagnosed: it could mean that the authorities concerned are losing track of patients in the stages which follow diagnosis. We are nevertheless not satisfied on the evidence which has come before us that chronic or potentially chronic illness is in fact being diagnosed systematically or early enough. This is a serious matter, since there are certain conditions which, if identified early, can be put right relatively quickly, but which, if neglected, may require prolonged treatment. In the rest of this chapter we examine the routes by which chronic or potentially chronic illness comes to notice at present, and make certain suggestions which we hope may help to close gaps.

Pre-school Children

12. Chronic illness in children below school age may at present come to the notice of the general practitioner, the local authority's child welfare service, or the hospital paediatrician. While in theory this network may appear adequate, we have reason to think that it is not consistently so, and that, for example, deafness, certain congenital malformations of the heart, and congenital dislocation of the hip are not always diagnosed sufficiently early.

13. We believe that the safeguards should start with the new-born infant. We understand that it is an increasing practice for children born in hospital to be examined by a paediatrician in the neo-natal period. We welcome this practice, and we recommend that wherever practicable it should be established as a matter of recognised routine in all maternity hospitals and maternity units. In the case of domiciliary confinements it should be the responsibility of the general practitioner, bearing in mind the assistance which can be obtained from specialists, to ensure that a full examination of the infant is carried out in the neo-natal period.

14. Regular clinical examinations during early childhood rank in our view as of equal importance with the examination of the new-born infant; and we consider that the aim should be to have all children examined by the general

practitioner or in a child welfare clinic during their first year of life and about the time of their second birthday. In these examinations special attention should be paid to physical, intellectual and emotional development.

15. There is of course an inherent difficulty in achieving the aim of regular examination. Parents will react quickly to some obvious and immediate danger such as an outbreak of infectious disease, and will readily take their children for immunisation: it is quite a different matter to encourage parents to have children examined when no obvious danger threatens or when they are not manifestly unwell. Parents must therefore be educated to see the vital importance of these examinations; and general practitioners, health visitors, and the medical and nursing staff of child welfare clinics should make a point of urging parents to co-operate in this way. There is one device which we understand has been used in some areas to back up these exhortations and which we commend for use elsewhere. A week or two before each examination is due the Medical Officer of Health sends parents a simple but explicit reminder of the fact and of the facilities available.

School Children

16. It is essential that there should be continuity in the oversight of children's health throughout childhood: we urge that all necessary measures should be taken to make sure that no gap occurs at this point in the process. In particular, the information — both medical and social — obtained about a child by the child welfare service should always be made available to the school health service; and there should be continuity whenever possible of medical and health visitor care.

17. Education authorities in Scotland have powers and duties in relation to the ascertainment of all children of school age in their areas who may require special educational treatment because of disability of mind or body. Nine categories of handicapped pupils are defined in the Special Educational Treatment (Scotland) Regulations, 1954, namely deaf, partially deaf, blind, partially sighted, mentally handicapped, epileptic, maladjusted, physically handicapped, and those suffering from speech defect. Special educational treatment is given in special schools, at home, or in hospital, although there are many who require but do not receive special school education. Full and timely ascertainment should uncover almost all young chronic sick people of school age in an area; but the thoroughness of ascertainment varies from one education authority to another, is often inadequate, and appears to some extent to be related to the availability of special schooling. Inadequate ascertainment may have serious consequences for the young chronic sick school child, whose future adjustment to society and whose opportunities for employment will depend very much on the level of education reached when he leaves school. It is of the greatest importance that such young people should be discovered as early in life as possible so that education appropriate to their capabilities can be given immediately the need arises.

18. Education authorities also have a duty to arrange for periodic medical examination of all children attending schools under their management and for the special examination of any child suspected by a parent, nurse, teacher, or other person to be suffering from disability. This arrangement of routine medical examination of all school children and the special examination during school life of those children thought to have some deviation from normal

physical or mental health provides the school health service with an opportunity to ascertain at an early stage the presence of illness or disability which might, in the absence of early treatment, lead to ill health later. We believe, however, that this opportunity is not being fully exploited, partly because of a lack of time for adequate examination and of proper accommodation for examinations to be held in privacy, and partly because of a failure to make parents realise how important it is for them to be present in order to assist the medical officer by providing background information. These shortcomings must be remedied if the school health service is to play a fully effective part in the early detection of chronic illness.

The Post-school Group

19. In this group we include young people between school-leaving age and the age of 35 which we ourselves fixed as the upper limit of our remit.

20. The young people who constitute this group — in which disabilities of a potentially chronic or crippling nature are still liable to arise *de novo* — pass a borderline at school leaving age in that they cease to be covered by the school health service. Some become covered by arrangements which give them the opportunity of periodic medical examination: such arrangements apply, for example, to university students and to nurses. Those young people coming within the scope of factories legislation have to be examined periodically by a factory doctor and certified as fit for the type of work on which they are engaged. There are however many whose health is not systematically safeguarded in these ways: among these are a large number employed in shops and offices who in our view should have legislative protection on the same lines as that afforded to factory workers. We recognise that there will inevitably be a number of young people for whom periodic examination can not be ensured in any formal way, and for these we think we should look to the general practitioner. General practitioners should as far as practicable encourage young people on their lists to have regular checks on their health if the nature of their employment does not ensure that this is done.

CHAPTER IV

REGISTRATION

21. The discoveries which we made about the lack of comprehensive statistical information on the young chronic sick prompted us to consider whether a register of such people would serve a useful purpose, and we made a point of inviting those who gave us oral evidence to consider this question. There was a fairly wide measure of support for the idea, and what was said on the subject helped us to see that a register could have other and indeed more important uses than the purely statistical.

Purposes of a Register

22. A register would, as we see it, have the following purposes:

(a) it would form a means of identifying individual patients' needs and

- of ensuring that handicapped people did not lose touch with services that could benefit them;
- (b) it could be an administrative tool in the hands of a co-ordinating agency for the various services involved in the care of the young chronic sick; and
- (c) it would provide in systematic form — for the purpose of planning services — a body of information about the incidence of particular diseases and their impact on the community.

Perhaps we may develop each of these points further.

23. As we have indicated in the preceding paragraph, we regard a register primarily as a means of meeting need and not as a source of statistical information. The evidence which we have received suggests that the needs of young chronic sick people are not always known to the authorities concerned, often because the patient is lost sight of when his needs have ceased to take an obvious and acute form such as hospital treatment. We think it essential that this breakdown of continuity should be avoided, and a register seems to us the likeliest means of achieving this aim.

24. We shall return in greater detail later in this report to the question of co-ordination of services: it may suffice at the moment to say that if co-ordination is to work in practice a central source of information about the patient and his needs is essential.

25. The value of a register for statistical purposes is not a point that need be laboured. We would like to say, however, that we are not advocating yet another form of record-keeping for its own sake: we hope that the information which a register would yield would have a direct practical application in the planning of the type, scale and location of services for the young chronic sick in each area of the country.

Keeping of a Register

26. We have reached the conclusion that the register for each area could most practicably be kept by the Medical Officer of Health concerned. We envisage that a patient's name would be placed on it — normally by the general practitioner — when chronic illness (as defined in paragraph 2 of this report) was first definitely diagnosed, and that it would contain enough up-to-date information about each patient to fulfil the purposes which we have suggested.

Access to a Register

27. The delicate question presents itself of the extent to which information about patients contained in the register should be made available to those who organise services. There is, on the one hand, the need to maintain a proper confidentiality about the clinical details of a patient's condition: on the other hand, there is the fact that, if the register is in practice to be a means of meeting need, information about the patient must be made available to those who run the services. The question of where to strike a balance arises particularly acutely where non-professional staff of voluntary and other organisations are concerned with services to the patient.

28. We do not think it practicable for us to lay down rules on this point; and we have reached the conclusion that the Medical Officer of Health must use his discretion in each particular case, interpreting the information about the patient as appropriate to the particular questioner.

Name of the Register

29. We are firmly of the view that a register of the kind which we are suggesting should not have a name including the words "chronic sick". We take this view because we believe that such a title would be discouraging to patients and their relatives, and that it would create in the public mind entirely the wrong impression about the purposes of the register. We suggest that the name might be something like "Register of the Young Handicapped".

Voluntary or Compulsory Registration

30. There has remained unanswered until now the key question about registration, i.e. whether it should be voluntary or compulsory. There are in fact two questions which should be distinguished — whether Medical Officers of Health should be obliged to maintain a register, and whether doctors should be obliged to place patients' names on it.

31. We regard the objects of a register as defined in paragraph 22 as being sufficiently important to justify our recommending that the keeping of a register by Medical Officers of Health should be made compulsory. It would be ideal if all local health authorities were prepared to maintain a register voluntarily, but it seems possible that on this basis there might be a tendency for each to wait for others to take the initiative; and it would probably be unrealistic to hope for voluntary acceptance of the idea in every area of the country. We understand that legislation would be necessary to make the keeping of a register compulsory; and we recommend that it should be enacted. We realise that this may take some time to achieve, but we hope that in the interval it may be possible by administrative means to encourage a number of local authorities to keep a register.

32. The more difficult question is whether doctors should be obliged to place patients' names on the register. Legislators in this country have in the past thought it justified to make notification of certain kinds of disease compulsory, the most obvious example being the notification of certain kinds of infectious disease; and we understand that in Denmark notification of chronic illness is compulsory. It is beyond doubt that the purposes of a register as we see them would be best served if notification were universal; but it is equally beyond doubt that many ordinary citizens understandably regard with suspicion and resentment anything which looks like a limitation of their personal freedom of choice. Such a limitation may be acceptable when without it an obvious danger to the community would exist — this is so in the instance of infectious diseases which we have just cited — but when there is no such obvious danger such measures are much more difficult to defend.

33. We have weighed up this matter with great care, and have reached the conclusion that we would not be justified in recommending compulsory registration of the young chronic sick. We consider that the register should contain only the names of those who are willing to have their name placed on it, or, in the case of children, those whose parents are so willing. We think that the best hope of securing acceptance of registration is to show patients and their relatives in a practical way that it is not simply yet another piece of bureaucracy, but an effective means of bringing them the services they need. The success of the system would depend entirely on the zeal, tact and imagination of those who operated it.

CHAPTER V

ASSESSMENT AND TREATMENT

34. Most if not all young chronic sick people have occasion sooner or later to make use of the services offered by hospitals. In this chapter we consider certain questions which have arisen in relation to these services.

Diagnosis and Assessment

35. Evidence which we have received suggests one important source of difficulty experienced by parents. Chronic illness often takes complex or multiple forms which call for protracted and diverse diagnostic procedures, and in these procedures there may be involved a number of different specialists whom it may not always be practicable to bring together at specific times for joint consultation. This means that the process of diagnosis and assessment of a child's condition may involve a series of visits to different clinics and sometimes to different hospitals.

36. At the end of this process, parents are sometimes left in a state of bewilderment as to the nature of a child's complaint and as to the kind of management which will be necessary if the child is subsequently to be cared for at home. They are likely to be in a state of emotional shock and to be faced with manifold problems in the family circle. It is therefore essential that practical advice and help should be immediately available to parents whenever required from the time of the initial diagnosis onwards, and that they should know where they can obtain these.

Counselling Centres

37. It is for this reason that we recommend the establishment of counselling centres. Such centres, as we envisage them, would be not only a source of clear and sympathetic guidance to parents, but would also give advice and help to young adults with chronic disability. Assuming that each centre performs this dual function, there should be a paediatrician to deal with those aspects of the work concerned with children and, for the older age group, a physician with a special interest in this kind of work. These specialists should of course have available to them all the information assembled by their fellow specialists about the patients concerned.

38. If the counselling centres are to carry out their functions successfully, patients should be referred to these centres by their own general practitioners, who should be closely associated with the work which goes on in them. The specialist in charge must also be supported by a team of representatives of the other services which may be needed. This team should include, for example, an almoner, a health visitor, and the Youth Employment Officer or his representative.

39. In the cities which have children's hospitals it may prove convenient to locate the counselling centres in these hospitals: elsewhere they can be established in whichever hospital seems best suited to the purpose.

In-patient Treatment

40. Many young people with long-term disabilities have to spend protracted periods in hospital, and for some the hospital inevitably becomes their home.

It is therefore of some importance to consider the type of unit in which they can most appropriately be cared for.

41. We accept wholeheartedly the view expressed by many of those who gave evidence to us that young hospital patients with chronic illness should not be placed in wards along with elderly long-term patients. This is bound to have a bad effect on the morale of the young people, and in so far as the practice still exists at all it should be abandoned forthwith.

42. Nor in our view is the ordinary acute ward with a mixed age population the right place for young long-term patients. Apart from the fact that it is uneconomic to use costly acute beds for such patients, we do not believe that it is in their own interests, since they find it discouraging to see other patients being restored to health and sent home while they themselves remain in hospital.

43. The right answer as we see it lies in the provision of units for young patients with long-term disabilities. These units may be in the same hospital as long-stay units for the elderly, but they should be physically separate and identifiable as units for the young. We believe that in such units young patients would find a niche for themselves in a way that would not be possible in a busy acute hospital, and that they would be happier. We recognise that if young patients are grouped in this way some may be at a distance from their relatives and friends. As we have indicated however, we think that there are compensating advantages; and we consider in any event that it would not be necessary to carry grouping of this kind to an unreasonable extent in geographical terms. There should be provided without delay an adequate number of hospital beds in the special units for those young chronic sick people who require continuing hospital care.

CHAPTER VI

ENVIRONMENTAL SERVICES

44. Many young chronic sick people do not need to be permanently in hospital and can be looked after adequately in their own homes provided that those who look after them receive a measure of support and help from the authorities concerned.

45. We understand that many housing authorities are already imaginative and understanding in providing suitable houses (e.g. ground floor houses) for families one of whose members is handicapped. We express the hope that all housing authorities can be persuaded to take similarly enlightened views of their responsibilities and that they will consider sympathetically requests for internal adaptations (e.g. of lavatories, bathrooms and steps) designed to make life easier for handicapped people.

46. It appears that in the past difficulties have arisen over questions of responsibility as between local authority and hospital authority for the provision of special equipment (e.g. lifting devices) for use in the home, but that, at least in the major centres of population, these difficulties have now been largely resolved. We need only express the hope in this context that all the authorities concerned will take a liberal view of their responsibilities and will not permit administrative arguments to delay the provision of necessary equipment for the homebound.

CHAPTER VII

DAY CENTRES AND RESIDENTIAL ACCOMMODATION

Day Centres

47. Reference was frequently made in the evidence which came before us to the need for day centres for the young chronic sick. As we see it, such centres may serve a number of different purposes, the most important of which are as follows:

- (a) to provide accommodation where children can be properly looked after while relatives are carrying out other necessary family duties;
- (b) to provide recreational facilities for children and young people; and
- (c) to provide occupational facilities for those able to make use of them.

48. This is a field in which voluntary organisations are already doing a great deal of good work. The work in day centres is in many ways suitable for voluntary endeavour, and we would welcome increased activity by voluntary organisations in providing this kind of service. We recognise that there may be financial difficulties involved in any major extension of this work; but we would urge voluntary organisations dealing with specific handicaps to combine with each other in an effort to avoid the unnecessary duplication of staff and facilities which may happen if each organisation goes its own way without regard to the efforts of others. We are not of course suggesting that voluntary organisations should carry the whole burden of providing day centres; and we look to local authorities to exercise more vigorously the powers which they already have.

Residential Accommodation

49. The young chronic sick may need residential accommodation, and this need may arise in a number of different ways. For example, a patient who has been looked after at home may find himself bereft of the relatives who were doing this, or the relatives may cease to be able to carry the burden. A young chronic sick person may be capable of training for or taking up a certain form of employment at a distance from home, but may need a measure of care or help which he cannot obtain in lodgings.

50. There is a great difficulty inherent in this question. This is that while the needs for residential accommodation for different age groups and types of disability are real there are not enough people in any area — except perhaps the most populous — to justify the setting up of special establishments. We understand that particular difficulties arise in relation to young people with multiple handicaps (e.g. the blind spastic), and that provision for this group is made at present only through the good offices of certain voluntary organisations.

51. There is no simple answer to this problem, and as far as we can see there are only two ways in which progress may be made. In the first place, we urge hospital authorities to take a liberal view of their responsibilities, particularly for those patients who have been cared for at home but who can no longer be looked after there for reasons such as we have described. In the second place, we express the hope that some of the large local authorities or voluntary organisations will find it possible to provide residential accommodation. Both for voluntary organisations (many of which have considerable experience in this field) and for local authorities there would be advantage in combining in groups

for this purpose, since financial burdens could be shared and the risk avoided of providing uneconomically small units catering for numerically small groups. In conclusion, we would like to stress that in our view the provision of one unit in Scotland for young chronic sick people with multiple handicaps is essential. Because of the need to have various specialist services readily available, such a unit would need to be closely associated with a major hospital.

CHAPTER VIII

EMPLOYMENT

52. The question of employment for the young chronic sick is perhaps on the fringe of our terms of reference, and we are glad to learn that this matter is in fact being studied at present by Working Parties set up by the British Council for Rehabilitation. We shall, therefore, confine ourselves in this report to recording three points which have been brought to our notice in this context.

53. The first is a general point. Many of those who gave evidence to us stressed the adverse effects on the morale of young chronic sick people which can be produced by a failure to employ suitably those who are employable, and — as a corollary — the stimulus afforded by a sense of being useful and of taking a place in the community. We were impressed by this evidence, and we hope that responsible authorities will take as much trouble as is necessary to help find suitable employment for those who can undertake it.

54. The second point relates to school-leavers. The view seems to be held in certain quarters that insufficient attention is given to the problems of the handicapped school-leaver, and that he is liable to drift into forms of employment which will suit him for only a short time. We think it possible that Youth Employment Officers may not always be sufficiently well informed about the working capacity of people suffering from certain forms of chronic illness, and that there may be a need for better liaison between Youth Employment Officers and medical services.

55. The final point to which we wish to call attention is the need to provide employment at home for those unable to work elsewhere. We realise that such provision is not easy, particularly in remote areas; but we think that the home-bound tend to be forgotten, and we urge all concerned to use initiative and enterprise on their behalf. We think it possible that the establishment of a register such as we have recommended earlier in this report might be one means of helping to secure employment for those who are confined to their homes.

CHAPTER IX

CO-ORDINATION OF SERVICES

56. The point which has been made most frequently and with the greatest emphasis in the evidence which has come before us is the lack of co-ordination which there is at the moment among the numerous agencies concerned with

the care of the young chronic sick. We are convinced that this state of affairs gives rise to unnecessary confusion, frustration, and duplication of effort; and it seems to us essential that it be put right.

57. Several witnesses favoured the establishment at local level of co-ordinating committees representative of all the interests concerned. There seems to us to be a danger that such committees would be unwieldy in size and ineffective in action. The aim of co-ordination is to produce prompt and effective service for the patient, and we have reached the conclusion that one individual should be clearly responsible. This person should be recognised by all concerned (a) as the source of all relevant information about available services in the area, and (b) as the person responsible for ensuring that appropriate services are brought into action as necessary.

58. Having considered the matter carefully, we have reached the conclusion that the local health authority, with the statutory responsibilities which they already have for care and after-care of the sick, would be the appropriate co-ordinating agency; and we recommend that the individual of whom we have spoken in the preceding paragraph should be an officer, preferably a Medical Officer, designated specifically for the purpose by the Medical Officer of Health. This officer, even when medical, would not, of course, have clinical responsibility for patients, but he would, for example, be the source of advice to general practitioners, hospital specialists, and almoners on the provision of domiciliary services. His other duties might appropriately include:

- (a) review of the register advocated in Chapter IV in order to make sure that patients were in touch with services;
- (b) provision of advice to relatives of the young chronic sick on available statutory and voluntary services — perhaps by attendance at the counselling centres suggested in Chapter V;
and
- (c) liaison between statutory and voluntary services.

59. It seems to us that the person charged with the co-ordinating responsibility would not be merely a "post office", but would have the opportunity to play a useful and constructive part in the provision of services. The success of his work would, of course, depend on the quality of his working relationship with the statutory and voluntary bodies concerned.

CHAPTER X

SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

Nature and Size of the Problem

- (1) The problem of the young chronic sick is essentially a problem of individual human needs, and should be tackled as such. There is a need for more comprehensive statistical information about the young chronic sick. (paragraph 10).

Ascertainment

- (2) Chronic or potentially chronic illness in young people is not always being diagnosed sufficiently early in life. (paragraph 11).

- (3) All infants born in hospital should be examined in the neo-natal period, and this examination should be carried out by a paediatrician wherever possible. All infants born at home should receive a similar examination, but this would ordinarily be the responsibility of the general practitioner. (paragraph 13).
- (4) During their first year of life and about the time of their second birthday all children should have a clinical examination by the general practitioner or in a child welfare clinic. General practitioners and local health authority staff must educate parents to recognise the importance of these examinations. (paragraphs 14–15).
- (5) There must be continuity in the oversight of children's health between the child welfare service and the school health service. (paragraph 16).
- (6) Arrangements within the school health service provide opportunities for the early ascertainment of illness or disability. These opportunities are not however being fully exploited, and this situation should be remedied. (paragraph 18).
- (7) Not enough young people in the post-school age group are at present covered by arrangements for regular medical examination. Legislative provision should be made for those employed in shops and offices; and general practitioners should have a particular care for others. (paragraph 20).

Registration

- (8) A register of the young chronic sick would serve a useful purpose in the identification of patients' needs, the co-ordination of services, and the assembling of statistical information. (paragraphs 21–25).
- (9) The register could best be maintained by the Medical Officer of Health for each area. (paragraph 26).
- (10) Decisions as to the use of information in the register should be made by the Medical Officer of Health. (paragraphs 27–28).
- (11) The name of the register should not include the words "chronic sick". (paragraph 29).
- (12) The keeping of a register by Medical Officers of Health should be made compulsory by legislation. (paragraph 31).
- (13) The register should contain only the names of patients who are willing to have their names included, or — in the case of children — whose parents are so willing. (paragraph 33).

Assessment and Treatment

- (14) Counselling centres should be established where parents can receive guidance on the management of chronic illness in children and where advice can be given to young adults with chronic disability. These centres should be under the charge of appropriate specialists; the cases should be referred by general practitioners, who should be closely associated with their work; and there should be a supporting team of representatives of the other services concerned. (paragraphs 37–38).
- (15) Young chronic sick hospital patients should not be accommodated along with elderly long-term patients or in acute wards, but in special units

by themselves. An adequate number of beds should be provided in such units without delay. (paragraphs 41 – 43).

Environmental Services

- (16) Housing authorities should do all they can to provide suitable accommodation for the handicapped. (paragraph 45).
- (17) Special equipment needed in the home should be supplied promptly. (paragraph 46).

Day Centres and Residential Accommodation

- (18) Day centres for the young chronic sick can serve a number of useful purposes. Voluntary organisations should combine in the provision of these centres, and local authorities should do their share. (paragraphs 47 – 48).
- (19) The young chronic sick may need residential accommodation for a number of different reasons. Statutory or voluntary organisations should try to meet this need; and might make best use of their financial resources by combining in groups within their own spheres. A unit is needed in Scotland for young people with multiple handicaps: such a unit would need to be associated with a major hospital. (paragraphs 49 – 51).

Employment

- (20) Every effort should be made to find suitable employment for young chronic sick people who are employable; and particular thought should be given to the problems of school-leavers and the homebound. (paragraphs 53 – 55).

Co-ordination of Services

- (21) There is a need for improved co-ordination of services for the young chronic sick. Responsibility for co-ordination should be placed on an officer — preferably a Medical Officer — appointed by the Medical Officer of Health in each area. (paragraphs 56 – 59).
- 60. We should like to take this opportunity of thanking Mr W. A. P. Weatherston, our Secretary until he left us to go to another Department in December, 1961; his most able successor Mr A. F. Reid; and our Assistant Secretary, Mr G. R. Wilson, for all the help and counsel they so unstintingly gave us. And finally we are greatly indebted to our Medical Assessor, Dr Laurie, for all the assistance he gave us and for being a tower of strength at all times.

MACDONALD,

Chairman, on behalf of the Committee.

APPENDIX

Organisations and Individuals from whom Evidence was received

Note: The written evidence of organisations and individuals marked * was supplemented by oral evidence.

Association of County Councils in Scotland
Association of School Medical and Dental Officers of Scotland
British Diabetic Association
British Medical Association, Scottish Office*
British Paediatric Association
British Red Cross Society, Scottish Branch *
Chartered Society of Physiotherapy
Cheshire Foundation Homes for the Sick (Scotland)
Convention of Royal Burghs
Dr Barnardo's Homes
Dundee Invalid and Cripple Children's Aid Association
Edinburgh Cripple and Invalid Children's Aid Society
Glasgow Poor Children's Fresh Air Fund and Cripple Children's League
Institute of Almoners (Scottish Regional Committee)*
Linn Moor Home for Ailing Children and Fresh Air Fortnight
Ministry of Labour and National Service
Ministry of Pensions and National Insurance
Multiple Sclerosis Society, Association of Scottish Branches
Muscular Dystrophy Group (Glasgow and District Branch)
National Assistance Board
National Association for the Paralysed
Phoenix Youth Club
Regional Hospital Boards in Scotland
Royal College of Nursing (Scottish Board)
Scottish Association of Executive Councils
Scottish Association of Occupational Therapists
Scottish Branch of the Haemophilia Society
Scottish Council for the Care of Spastics *
Scottish Council of the College of General Practitioners
Scottish Counties of Cities Association
Scottish Education Department
Scottish Epilepsy Association *
Scottish Health Visitors' Association
Society of Medical Officers of Health (Scottish Branch) *
Trefoil Residential School for Physically Handicapped Children
Professor E. M. Backett, B.Sc., M.B., B.S., D.P.H., M.R.C.P. (Lond.), F.S.S.
Assistant County Commissioner for Handicapped Scouts (County of Glasgow)
J. Romanes Davidson, Esq., M.D.
J. W. Farquhar, Esq., M.D., F.R.C.P. (Ed.)
T. T. S. Ingram, Esq., M.D., F.R.C.P. (Ed.), D.C.H. (Eng.) *
Professor A. Mair, M.D., D.P.H., D.I.H. (Lond.)
Medical Officer of Health for Dunfermline
G. A. Pollock, Esq., M.B., Ch.B., F.R.C.S. (Ed.), F.A.C.S., D.P.H.
R. Deans Weir, Esq., M.B., Ch.B., D.P.H. *

Oral Evidence Only

Professor T. Ferguson, C.B.E., M.D., D.Sc.Ed., D.P.H., F.R.F.P.S. Glas., F.R.C.P. Ed., F.R.S. Ed.
J. F. Montgomerie, Esq., I.S.O., D.C.M.